

Self-Perceived Stigma and Barriers to Testing and Treatment for Hepatitis C: A Mixed Method Study

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Abstract

Background: Hepatitis C virus (HCV) infection remains an important public health concern, particularly in rural populations where stigma, inadequate knowledge and difficulties in accessing healthcare may delay diagnosis and treatment. Understanding self-perceived stigma and barriers to HCV care is essential for improving engagement with treatment services.

Aims: To estimate the prevalence of self-perceived stigma among HCV-positive patients, identify barriers associated with HCV testing and treatment, and explore healthcare providers' perspectives regarding these barriers.

Materials and Methods: A hospital-based mixed-method study was conducted among 170 HCV-positive patients at the Hepatitis C Clinic/Medicine OPD of BPS Government Medical College for Women, Khanpur Kalan, Sonapat, Haryana, from August 2023 to November 2024. Consecutive sampling was used. Stigma was assessed using the 33-item Hepatitis C Virus Stigma Scale. The qualitative component included 4 FGDs and 8 IDIs involving patients and healthcare providers.

Results: The mean age was 45.90 ± 15.55 years; 50.6% were male and 49.4% female, while 78.2% were rural residents. Illiteracy was reported in 34.7%, and 52.9% had a monthly family income below ₹10,702. Symptom-based diagnosis was most common (48.2%), and 77.1% had been diagnosed within 0–3 months. Treatment initiation occurred within 1–3 months in 41.8%. Overall, 28.2% experienced self-perceived stigma. Stigma was significantly associated with age ($p < 0.001$) and other drug addiction ($p = 0.027$), but not sex ($p = 0.263$), caste ($p = 0.340$), education ($p = 0.065$) or comorbidity ($p = 0.313$). No high-risk behaviour showed a statistically significant association with stigma.

Conclusion: Self-perceived stigma affected a substantial proportion of participants and was associated particularly with age and drug addiction. Improved awareness, stigma-sensitive counselling and accessible, timely HCV services are needed.

Keywords: Hepatitis C; Stigma; Testing barriers; Treatment barriers; Rural health; HCV

Introduction

Hepatitis C virus (HCV) infection remains an important global public health problem because of its potential to cause chronic hepatitis, cirrhosis, hepatocellular carcinoma and premature mortality. Despite major advances in diagnosis and the availability of highly effective direct-acting antiviral therapy, substantial gaps persist across the HCV care cascade. In 2019, only about one-fifth of people living with chronic HCV infection globally had been diagnosed, highlighting the continuing challenge of timely case detection and linkage to care [1]. Although simplified diagnostic and treatment approaches have increasingly made HCV care more accessible, barriers related to health-system organisation, affordability, accessibility, knowledge and continuity of care continue to affect uptake [2].

Stigma is an important but comparatively less visible barrier to HCV prevention, testing and treatment. HCV-related stigma may arise from misconceptions about transmission, association of the infection with substance use or other socially disapproved behaviours, and fear of disclosure or negative reactions from family and community. Evidence suggests that stigma is widely experienced among people living with HCV and may influence healthcare-seeking behaviour and engagement with treatment services [3]. The validated 33-item HCV Stigma Scale has further facilitated systematic assessment of patients' perceptions and experiences of HCV-related stigma [4].

Barriers to testing are often multifactorial. Fear of a positive diagnosis, limited knowledge, perceived low personal risk, stigma, previous negative experiences with healthcare services and inadequate provider-patient communication have been identified as important obstacles [5]. Similar challenges may continue after diagnosis, with treatment initiation and completion being affected by misinformation, competing personal priorities, inconvenient services, inadequate counselling and perceived inaccessibility of healthcare [6]. These barriers may be particularly relevant in rural and underserved

populations, where healthcare access and continuity can be difficult.

The present study was undertaken to assess self-perceived stigma among Hepatitis C-positive patients receiving care at a rural tertiary-care hospital in Haryana. It also aimed to identify the major barriers faced by patients in accessing Hepatitis C testing and treatment. In addition, the study explored healthcare providers' perspectives and experiences regarding the factors that hinder timely testing, treatment initiation and continued care.

MATERIALS AND METHODS

Study Design: Hospital-based mixed-method study.

Study Population: Adults with confirmed Hepatitis C infection registered at the Hepatitis C clinic, along with healthcare providers involved in HCV care.

Sample Size: 170 participants.

Study Duration: August 2023 to November 2024.

Study Setting/Location: Medicine OPD/Hepatitis C Clinic, Bhagat Phool Singh Government Medical College for Women (BPSGMCW), Khanpur Kalan, Sonapat, Haryana.

Inclusion Criteria:

- Confirmed Hepatitis C infection.
- Age ≥ 18 years.
- Registered at the Hepatitis C clinic.
- Willing to participate.
- Healthcare providers involved in HCV care and willing to participate.

Exclusion Criteria:

- Patients who were seriously ill and required hospital admission.
- Patients unable to comprehend or participate in the interview.

- Healthcare providers who were co-supervisors of the thesis protocol.
- Providers working in the Hepatitis C clinic for less than 3 months.

Qualitative Component

Four FGDs were conducted, with 6–10 participants per group, lasting approximately 30 minutes. Eight IDIs were conducted—four with patients and four with healthcare providers; interviews lasted approximately 30–45 minutes and were audio-recorded with consent.

Statistical Analysis: Data were entered and managed using Microsoft Excel 2021 and

subsequently analysed using IBM SPSS Statistics version 20. Quantitative data were summarised using mean $\pm$ standard deviation (SD), frequency, and proportion, as appropriate. Associations between categorical variables were assessed using the Chi-square test, while Fisher's exact test was applied wherever the expected cell frequencies were small or where appropriate. A p -value of <0.05 was considered statistically significant. For qualitative data, the recorded information was transcribed, followed by systematic coding and categorisation, and subsequently analysed using thematic analysis based on the six-stage framework.

Result

Table 1. Sociodemographic and Clinical Profile of Study Participants

Variable	Category	n	%
Age (years)	18–27	18	10.6
	28–37	44	25.9
	38–47	32	18.8
	48–57	33	19.4
	58–67	24	14.1
	≥ 68	19	11.2
	Mean age $\pm$ SD	45.90 $\pm$ 15.551	
Sex	Male	86	50.6
	Female	84	49.4
Residence	Rural	133	78.2
	Urban	37	21.8
Education	Illiterate	59	34.7
	Primary	22	12.9
	Middle	30	17.6
	Matric	27	15.9
	Secondary	21	12.4
	Graduate	9	5.3
	Postgraduate	2	1.2
Occupation	Farmer	31	18.2
	Homemaker	53	31.2
	Labourer	33	19.4
	Private	12	7.1
	Self-employed	31	18.2
	Government job	10	5.9
Family income (Rs/month)	$<10,702$	90	52.9
	10,703–31,977	63	37.1
	31,978–53,360	15	8.8
	53,361–80,109	1	0.6
	80,110–106,849	1	0.6
Marital status	Married	148	87.1
	Unmarried	9	5.3
	Widow/widower	13	7.6

Table 2. HCV Diagnosis, Treatment Initiation, and High-Risk Behaviour Profile of Study Participants

Variable	Category	n	%
Mode of diagnosis	Symptomology	82	48.2
	Preanesthetic check-up	33	19.4
	Medical check-up	24	14.1
	Blood donation	12	7.1
	Admission	10	5.9
	ANC check-up	9	5.3
Time since diagnosis	0–3 months	131	77.1
	4–6 months	6	3.5
	7–9 months	8	4.7
	10–12 months	5	2.9
	>12 months	20	11.8
Diagnosis → treatment	No gap	50	29.4
	<1 month	28	16.5
	1–3 months	71	41.8
	4–6 months	6	3.5
	7–9 months	3	1.8
	10–12 months	6	3.5
	>12 months	6	3.5
High-risk behaviour level	None	30	17.6
	Low	134	78.8
	Moderate	6	3.5
Specific high-risk history	Body piercing	93	54.7
	Tattooing	65	38.2
	Blood transfusion	29	17.1
	HCV in family	32	18.8
	Unsafe sexual practice	20	11.8
	Sharing razors	8	4.7
	Injectable drug use	5	2.9
	Needle-stick injury	1	0.6

Table 3. Self-Perceived Stigma and Its Association with Important Participant Characteristics

Reason for delay	n	%
Others	50	29.4
Inaccessible treatment facilities	31	18.2
Inadequate knowledge regarding HCV/treatment	20	11.8
Considered treatment non-urgent/untreatable	14	8.2
Ongoing high-risk behaviour	2	1.2
Financial constraints	2	1.2
Concern regarding medication side effects	1	0.6

Table A. Overall Self-Perceived Stigma

Self-perceived stigma	n	%
Present	48	28.2
Absent	122	71.8
Total	170	100

Table B. Association of Self-Perceived Stigma with Important Participant Characteristics

Variable	Category	Stigma present n (%)	Stigma absent n (%)	p-value
Age	18–27 yr	12 (66.7)	6 (33.3)	<0.001
	28–37 yr	18 (40.9)	26 (59.1)	
	38–47 yr	7 (21.9)	25 (78.1)	
	48–57 yr	5 (15.2)	28 (84.8)	
	58–67 yr	20 (83.3)	4 (16.7)	
	≥68 yr	17 (89.5)	2 (10.5)	
Sex	Male	21 (24.4)	65 (75.6)	0.263
	Female	27 (32.1)	57 (67.9)	
Caste	General	18 (23.7)	58 (76.3)	0.34
	OBC	17 (28.8)	42 (71.2)	
	SC/ST	13 (37.1)	22 (62.9)	
Education	Illiterate	13 (22.0)	46 (78.0)	0.065
	Primary	7 (31.8)	15 (68.2)	
	Middle	6 (20.0)	24 (80.0)	
	Matric	6 (22.2)	21 (77.8)	
	Secondary	10 (47.6)	11 (52.4)	
	Graduate+	6 (54.5)	5 (45.5)	
Alcohol intake	Yes	10 (45.5)	12 (54.5)	0.054
	No	38 (25.7)	110 (74.3)	
Other drug addiction	Yes	5 (62.5)	3 (37.5)	0.027
	No	43 (26.5)	119 (73.5)	
Comorbidity	Present	8 (21.6)	29 (78.4)	0.313
	Absent	40 (30.1)	93 (69.9)	

Table 4. Association of High-Risk Behaviours with Self-Perceived Stigma among Study Participants

High-risk behaviour	History present: stigma n (%)	History absents: stigma n (%)	p-value
Unsafe sexual practice	8 (40.0)	40 (26.7)	0.213
Injectable drug use	3 (60.0)	45 (27.3)	0.137
Tattooing	18 (27.7)	30 (28.6)	0.902
Sharing razors	2 (25.0)	46 (28.4)	0.835
Body piercing	31 (33.3)	17 (22.1)	0.105
Blood transfusion	4 (13.8)	44 (31.2)	0.058
Needle-stick injury	1 (100)	47 (27.8)	0.282
HCV in family	13 (40.6)	35 (25.4)	0.084

Among the 170 study participants, the mean age was 45.90 ± 15.55 years. The largest proportion belonged to the 28–37-year age group (25.9%), followed by 48–57 years (19.4%) and 38–47 years (18.8%). Males and females were almost equally represented, accounting for 50.6% and 49.4%, respectively. The majority of participants were from rural areas (78.2%). Regarding education, 34.7% were illiterate, while only 5.3% and 1.2% were graduates and

postgraduates, respectively. Homemakers constituted the largest occupational group (31.2%), followed by labourers (19.4%), farmers (18.2%) and self-employed individuals (18.2%). More than half of the participants (52.9%) had a monthly family income below ₹10,702. Most participants were married (87.1%), indicating that the study population was predominantly rural, married and from lower-income backgrounds.

Symptom-related presentation was the most common mode of HCV diagnosis, accounting for 48.2% of participants, followed by preanaesthetic check-up (19.4%) and routine medical check-up (14.1%). Most participants (77.1%) had been diagnosed within the previous 0–3 months. Following diagnosis, 41.8% initiated treatment within 1–3 months, while 29.4% had no gap between diagnosis and treatment initiation. High-risk behaviour was classified as low in 78.8%, while 17.6% reported no such behaviour and 3.5% had moderate-risk behaviour. Among specific risk histories, body piercing (54.7%) was most frequent, followed by tattooing (38.2%), HCV in the family (18.8%) and previous blood transfusion (17.1%). Injectable drug use was reported by 2.9%, while needle-stick injury was least frequent (0.6%). Overall, 48 (28.2%) participants experienced self-perceived stigma, whereas 122 (71.8%) did not. Among reported reasons for delay in testing or treatment, “other” reasons were most frequently cited (29.4%), followed by inaccessible treatment facilities (18.2%) and inadequate knowledge regarding HCV and its treatment (11.8%). Self-perceived stigma showed a statistically significant association with age ($p < 0.001$), with stigma particularly frequent among participants aged 18–27 years (66.7%), 58–67 years (83.3%) and ≥ 68 years (89.5%). No significant association was observed with sex ($p = 0.263$), caste ($p = 0.340$) or education ($p = 0.065$). Alcohol intake showed a borderline association ($p = 0.054$), while other drug addiction was significantly associated with stigma ($p = 0.027$). Comorbidity was not significantly associated with stigma ($p = 0.313$). The analysis did not demonstrate a statistically significant association between any of the individual high-risk behaviours and self-perceived stigma. Stigma was reported by 40.0% of participants with a history of unsafe sexual practices compared with 26.7% without such a history ($p = 0.213$). Among those reporting injectable drug use, 60.0% experienced stigma compared with 27.3% among those without this history, although the association was not statistically significant ($p = 0.137$). Stigma

prevalence was similar among participants with and without tattooing (27.7% vs 28.6%; $p = 0.902$) and sharing razors (25.0% vs 28.4%; $p = 0.835$). Body piercing showed a somewhat higher proportion of stigma (33.3% vs 22.1%), but this did not reach statistical significance ($p = 0.105$). Similarly, no significant association was found with blood transfusion ($p = 0.058$), needle-stick injury ($p = 0.282$), or a family history of HCV ($p = 0.084$).

Discussion

The present study was conducted among 170 patients receiving care for hepatitis C at a rural tertiary-care hospital in Haryana and provides useful insight into the demographic profile, pathways to diagnosis and treatment, self-perceived stigma, and behavioural factors associated with stigma.

The mean age of participants was 45.90 ± 15.55 years, with the largest proportion belonging to the 28–37-year age group (25.9%). Males and females were almost equally represented (50.6% and 49.4%), while a marked majority were from rural areas (78.2%). The predominance of rural participants is understandable given the location and referral catchment of the study hospital. The educational profile also suggested considerable socioeconomic disadvantage, with 34.7% being illiterate and more than half reporting a monthly family income below ₹10,702. Similar socioeconomic patterns have been described in Indian studies of HCV, where rural residence, lower educational attainment and occupational groups such as farmers and labourers constitute an important proportion of affected populations. A hospital-based case-control study from Punjab identified several epidemiological risk factors for HCV infection, including blood transfusion, dental procedures, intravenous injection or infusion from unqualified practitioners, injectable and non-injectable drug use, tattooing, and piercing [7]. These findings highlight the importance of accessible, community-oriented HCV education and testing strategies in rural populations.

In the present study, nearly half of the participants (48.2%) were diagnosed following

symptoms, whereas only 14.1% were identified during routine medical check-up. This suggests that a considerable proportion of infections may still be detected after individuals become symptomatic rather than through proactive screening. Similar concerns have been reported internationally, with studies showing low uptake of HCV testing and identifying limited awareness, perceived low risk and fear of diagnosis as important barriers to testing [8]. The finding is particularly relevant because HCV infection may remain clinically silent for prolonged periods.

Most participants (77.1%) had been diagnosed within three months of assessment. Although 29.4% started treatment without any gap after diagnosis, the largest group (41.8%) experienced a 1–3-month interval between diagnosis and treatment. This delay is consistent with evidence that the HCV care cascade frequently involves losses between diagnosis, confirmatory evaluation, linkage and treatment initiation. A systematic review and meta-analysis found that simplified testing strategies, patient education, care coordination and patient navigation can significantly improve testing, linkage and treatment initiation [9]. Thus, reducing the interval between diagnosis and treatment should remain an important component of HCV elimination programmes.

Body piercing was the most frequently reported specific risk history in the present study (54.7%), followed by tattooing (38.2%) and previous blood transfusion (17.1%). These findings are broadly consistent with Indian evidence identifying unsafe injections, body piercing, tattooing and other healthcare-related exposures as important potential routes associated with HCV infection [10]. A tertiary-care case-control study from Punjab similarly identified blood transfusion, unsafe injections, tattooing, piercing and injecting drug use among significant epidemiological correlates of HCV infection [7]. However, the present study describes the frequency of reported exposures among already diagnosed patients and therefore should not be interpreted as establishing causal associations.

Overall, 28.2% of participants reported self-perceived stigma, while 71.8% did not. Although this indicates that stigma was not experienced by the majority, more than one in four participants reporting stigma represents a clinically and socially important finding. The prevalence was lower than that reported in a study by Saine et al., in which most participants with a history of HCV experienced some degree of HCV-related stigma [3]. Differences may relate to variations in study populations, healthcare settings, stigma measurement, disease stage and social context. Importantly, HCV stigma is not limited to overt discrimination; it can also involve anticipated negative reactions, concerns about disclosure and internalised negative beliefs. Qualitative synthesis of HCV stigma research has emphasised that stigma is shaped by broader social and institutional processes rather than by individual behaviour alone [11].

The present study found a strong association between age and self-perceived stigma ($p < 0.001$). Stigma was particularly high among participants aged 18–27 years (66.7%), 58–67 years (83.3%) and ≥ 68 years (89.5%). This pattern differs from studies in which demographic characteristics have not consistently predicted HCV stigma. Saine et al. reported that determinants of stigma varied according to HIV/HCV status and that several demographic and socioeconomic factors did not show uniform effects across groups [12]. Accurate HCV RNA testing is important for confirming active infection following initial HCV antibody detection [13]. The apparently higher stigma in the youngest and oldest age categories in the present study may therefore reflect differences in social circumstances, perceived vulnerability, family dependence or concerns about disclosure, but these explanations require further qualitative exploration.

No statistically significant association was observed between stigma and sex ($p = 0.263$), caste ($p = 0.340$), education ($p = 0.065$), or comorbidity ($p = 0.313$). Education showed a trend towards variation, with stigma being more

frequently reported among participants with secondary or graduate-level education, but the association did not reach statistical significance. These findings support the view that HCV-related stigma can cut across conventional sociodemographic categories and should not be assumed to be restricted to a particular educational or social group.

A statistically significant association was observed between other drug addiction and self-perceived stigma ($p=0.027$). Among participants reporting drug addiction, 62.5% experienced stigma compared with 26.5% among those without such a history. This finding is consistent with previous research showing that HCV stigma may become particularly pronounced when infection is socially linked with drug use. Qualitative research among people experiencing homelessness has identified limited knowledge and misconceptions about HCV, mistrust of healthcare providers, substance-use-related comorbidity and social stigma as important barriers to HCV care [14]. Evidence from a global systematic review and meta-analysis suggests that decentralisation and integration of HCV testing, care and treatment can improve access to testing, linkage to care and treatment, while task-shifting to non-specialist providers can achieve similarly high cure rates [15].

Alcohol intake was not statistically significantly associated with self-perceived stigma ($p=0.054$), although stigma was more frequently reported among participants who reported alcohol intake, with stigma reported by 45.5% of participants who consumed alcohol compared with 25.7% of those who did not. Although this did not meet the predefined level of statistical significance, the finding may indicate a possible relationship between socially stigmatised behaviours and perceptions surrounding HCV. Further studies with larger samples would be required to establish whether this represents a genuine association.

Among reported reasons for delay, 29.4% cited other reasons, while 18.2% reported inaccessible treatment facilities and 11.8% reported inadequate knowledge regarding HCV or its treatment. Smaller proportions considered

treatment non-urgent or untreatable (8.2%), while financial constraints and ongoing high-risk behaviour each accounted for 1.2%. Previous research on community-based HCV treatment has similarly identified socioeconomic circumstances, internalised stigma, lack of knowledge, limited patient support and health-system barriers as important factors affecting engagement with HCV treatment [12]. Previous research has similarly identified limited knowledge, fear of diagnosis, stigma, poor healthcare access and inadequate communication as important obstacles to HCV testing and treatment [8]. Recent patient-journey research has additionally demonstrated that difficult physical access, complex healthcare navigation and inadequate counselling can delay treatment initiation, while family support can facilitate engagement with care [16].

The relatively small proportion citing financial constraints may reflect the availability of government-supported HCV services in the study setting. Nevertheless, indirect costs such as transportation, time away from work and repeated visits may remain important even when medicines are available at low or no direct cost. Indian evidence on treatment discontinuation has shown that relocation and lack of time because of work or personal responsibilities can contribute substantially to interruption of HCV treatment [17].

None of the individual high-risk behaviours showed a statistically significant association with self-perceived stigma. Although stigma was more common among participants reporting unsafe sexual practices (40.0%), injectable drug use (60.0%), and body piercing (33.3%), the corresponding p -values were 0.213, 0.137 and 0.105, respectively. Similarly, tattooing, razor sharing, blood transfusion, needle-stick injury and family history of HCV were not significantly associated with stigma. The absence of statistically significant associations may partly reflect the small numbers in several exposure categories, particularly injectable drug use and needle-stick injury, and therefore should not necessarily be interpreted as evidence that

these behaviours have no relationship with stigma.

Overall, the findings indicate that self-perceived stigma affected a substantial minority of HCV-positive patients and was particularly associated with age and drug addiction, while several conventional sociodemographic and individual risk factors were not significantly related to stigma. The barriers identified in the study also point towards the need for patient education, stigma-sensitive counselling, simplified access to testing and treatment, and stronger linkage between diagnosis and treatment. These approaches are consistent with evidence supporting integrated, patient-centred models of HCV care [9,16].

Conclusion

The present mixed-method study demonstrates that self-perceived stigma remains an important concern among patients with Hepatitis C, with 28.2% of participants reporting stigma. Stigma was significantly associated with age and other drug addiction, whereas sex, caste, education, alcohol intake, and comorbidity did not show statistically significant associations. Diagnosis was most commonly made following symptoms, and a considerable proportion experienced a delay between diagnosis and treatment initiation. Inadequate knowledge and limited accessibility of treatment facilities emerged as important barriers to care. Although individual high-risk behaviours were not significantly associated with stigma, higher proportions of stigma were observed among participants reporting injectable drug use, unsafe sexual practices and body piercing. Overall, the findings emphasise the need for early diagnosis, improved patient education, stigma-sensitive counselling, accessible treatment services, and stronger linkage between diagnosis and treatment. Addressing both patient- and healthcare-related barriers may improve engagement with HCV care and support progress towards Hepatitis C elimination.

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Ethical approval was obtained from the Institutional Ethics Committee of Bhagat Phool Singh Government Medical College for Women, Khanpur Kalan, Sonipat, Haryana, India, before commencement of the study. Written informed consent was obtained from all participants before their participation in the study.

Availability of data and materials: The datasets generated and/or analysed during the current study are not publicly available because they contain participant-related information but may be available from the corresponding author on reasonable request, subject to applicable ethical and institutional restrictions.

Competing interests: The authors declare that they have no competing interests.

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Informed consent for interviews and audio recording:

Written informed consent was obtained from participants involved in the qualitative component before conducting the focus group discussions and in-depth interviews. Participants were informed about the purpose of the study, voluntary nature of participation, confidentiality, and audio recording procedures. The manuscript states that the qualitative interviews were audio-recorded with consent.

Use of Artificial Intelligence (AI) Tools: The authors used an artificial intelligence (AI)-based language tool solely for grammatical correction, spelling, punctuation, and improvement of language clarity. The AI tool was not used for study design, data collection, data analysis, interpretation of results, generation of scientific content, or formulation of conclusions. The authors take full responsibility for the accuracy, originality, and integrity of the content of the manuscript.

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